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## BEST PRACTICE

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### Special Needs Registries: Overview of Registry Issues

#### PURPOSE

This Best Practice provides an overview of issues commonly encountered by jurisdictions that are planning to establish or have already established a special needs registry.

#### SUMMARY

A special needs registry is commonly a list of individuals within a jurisdiction who require assistance before, during, or after an emergency. Persons with disabilities or other functional needs often voluntarily submit either residential, medical, functional, or social background and contact information to their jurisdiction's registry so that emergency management, response, and other personnel can better assist them during an emergency.

#### *About This Series of Best Practices*

This Best Practice is part of the Special Needs Registries Best Practice Series. This series provides information about common challenges faced by jurisdictions when establishing and operating registries as well as practices taken to overcome them. The series supports jurisdictions in the process of creating, maintaining, or improving a special needs registry. These Best Practices present information about successful practices undertaken by jurisdictions and how these jurisdictions have addressed common challenges.

This Best Practices series comprises the following documents:

- Overview of Registry Issues
- Information Access, Collection, and Maintenance
- Registration Process
- Promoting the Registry

#### *About This Best Practice Overview*

This Best Practice document provides an overview of issues that are important to consider in establishing, operating, or maintaining a special needs registry. It consists of the following sections:

- About This Series of Best Practices
- About This Best Practice Overview
- Terminology
- Purposes of Registries
- Registry Eligibility
- Federal and State Guidance for Special Needs Registries
- Challenges
- Staffing

## DESCRIPTION

### Terminology

Jurisdictions use various terms to refer to special needs registries depending on the function of the registry and the populations they serve. "Special needs registry" is the most common term used for these registries. However, other terms include "emergency evacuation assistance registry," "vulnerable populations registry," and "medical needs registry." In this document, the term "special needs registry" is used broadly and inclusively to refer to all types of registries.

### Purposes of Registries

A special needs registry provides emergency management and response personnel with information about the location and requirements of individuals with disabilities and other functional needs. Jurisdictions use their special needs registries for a variety of purposes. The most commonly used purposes are emergency dispatch, evacuation assistance, inquiry into the safety status of registrants, and logistics and planning.

### Emergency Dispatch

Some jurisdictions use special needs registries to provide emergency dispatchers with information about individuals with disabilities or other functional needs. This information informs and assists response personnel in the event of an emergency. Information that individuals submit to the registry is referred to emergency dispatchers when the individuals call 9-1-1 or another emergency phone number.

### Evacuation Assistance

Some jurisdictions use their special needs registries to provide evacuation assistance to registrants. Personnel responsible for managing registries in these jurisdictions will contact each registrant after an evacuation order is issued to ensure that he or she has received the evacuation notice and to inquire about his or her evacuation plan. Some jurisdictions offer transportation assistance to registrants as well. A small number of jurisdictions assist registrants with making arrangements for their non-service animal pets during an evacuation.

### Inquiry into Safety Status of Registrants

Many special needs registries provide emergency management personnel with a means to verify the safety of registrants prior to, during, or following an incident. Personnel who manage registries or their volunteers call registrants in the event of an emergency to determine if any assistance is needed. These personnel may also periodically contact registrants to provide emergency information and guidance to ensure that they will be prepared for an incident.



**Registration Web Page for Dane County, Wisconsin, Emergency Management's Disaster Assistance Voluntary Registry**

## Logistics and Planning

Special needs registries provide jurisdictions with information that can facilitate logistics planning during an emergency. Registries can inform jurisdictions of the location of populations with disabilities and other functional needs so that appropriate reception centers or accommodable shelters can be established in those locations. For example, the Jefferson Parish, Louisiana, Assisted Evacuation Assessment Registry provides the parish with information about the number of individuals who may require assistance during an evacuation and the needs of those individuals. The registry is used for assessment and planning purposes only. Additionally, jurisdictions use registries to identify the type and quantity of medical equipment required by registrants to better assess their equipment inventory decisions.



Utah Special Needs Registry Home Page

## Registry Eligibility

Registry eligibility varies widely according to jurisdiction. Some jurisdictions define registry eligibility as a broad range of functional or access needs while other jurisdictions use more specific definitions for eligibility, such as medical needs. For example, the Bucks, Chester and Montgomery Counties, Pennsylvania, Special Needs Registry serves any individual that “cannot receive, understand, or act upon emergency protective orders.” In contrast, the Orange County, North Carolina, Department of Social Service’s Special Needs Registry provides a list of seven specific categories to describe the individuals it serves. Further, some registries, such as Iredell County, North Carolina, Emergency Management’s Special Needs Registry, offer services to individuals with limited English proficiency, while other jurisdictions do not consider this factor to be a qualifying condition for participation in their registries.

Registries may be named to reflect the eligible populations that they serve. For example, the Fairfax County, Virginia, Office of Emergency Management’s Special Needs Registry is divided into two registries that serve different populations. The Fairfax County Medical Needs Registry serves individuals with medical needs; the Social Needs Registry serves organizations that assist individuals who are considered to be vulnerable, at-risk, or hard-to-reach during an emergency, but who do not meet the definition of having medical needs.

## Federal and State Guidance for Special Needs Registries

Federal and state governments have issued guidance about establishing and operating a special needs registry. The guidance addresses various actions that should be taken by jurisdictions and identifies issues for jurisdictions to consider before establishing a special needs registry. The sections below list steps recommended by the Department of Homeland Security (DHS) and the Federal

See the California Emergency Management Agency’s [Guidance on Planning and Responding to the Needs of People with Access and Functional Needs, Identification of People with Disabilities and Older Adults](#) for more registry guidance.

Emergency Management Agency (FEMA) as well as New Hampshire and California for establishing and operating a special needs registry.

### Steps to Take Before Establishing a Registry

- **Collaborate with individuals and community partners to determine registry requirements:** Jurisdictions should coordinate with individuals with disabilities and other functional and access needs and the community organizations and government agencies that serve these individuals to determine how the registry should function. This coordination can help jurisdictions to decide what type of registry—such as medical, functional, or social—will best serve the community.
- **Consider the costs of maintaining a registry:** Jurisdictions should consider how they will fund the costs of maintaining a registry in their planning process.
- **Establish a process to determine eligibility for the registry:** Jurisdictions must identify what factors are required for registration and who will make the decision to include or not include individuals in the registry. Federal guidance recommends that, in general, registries should be reserved for individuals who live in their own homes, since residential facilities should already have emergency plans in place for their residents.
- **Address Health Insurance Portability and Accountability Act (HIPAA) restrictions and other legal liabilities:** Special needs registries often require that individuals submit sensitive medical and background information. Thus, jurisdictions should ensure that they have taken the proper steps to meet HIPAA and other legal requirements in handling the information.

See DHS's [Individuals with Disabilities in Emergency Preparedness Annual Guidance Report 2005](#) for more registry guidance.

### Steps to Take for Registry Management

- **Ensure confidentiality of information on the registry:** Jurisdictions should consider what steps must be taken to protect information. They should also determine which officials will have access to the information. Ideally, access to information should be on a need-to-know basis.
- **Maintain information:** Jurisdictions should decide how to record information submitted by new registrants. Additionally, Federal guidance states that jurisdictions should establish a process for registrants to re-register at least annually. This ensures that their information is up-to-date and confirms that the registrants still require registry services.
- **Anticipate participation challenges:** Individuals may be reluctant to participate in registries for various reasons, such as an unwillingness to share personal information with a government organization. Jurisdictions should identify methods of communicating the purpose of the registry to eligible individuals to reassure eligible individuals that their personal information will be protected.

See FEMA's [Interim Emergency Management Planning Guide for Special Needs Populations](#), Appendix E, for more registry guidance.

### Steps to Take to Communicate Important Information

- **Ensure that registration is voluntary:** Jurisdictions should communicate that registration and participation are voluntary. They should also inform individuals that registration can be withdrawn at any time.

- **Explain what registration means for registrants:** Registrants should have a clear understanding of what services may be available to them as a result of participating in the registry. They should understand that registration does not guarantee response priority. Registrants should always be urged to contact their jurisdiction's designated emergency phone number in an emergency.
- **Emphasize the importance of personal preparedness plans:** Jurisdictions should emphasize the need for registrants to develop personal preparedness plans. Registrants should not rely on registries as their only emergency or evacuation plan.

See [New Hampshire State Emergency Operations Plan Support Annex: Functional Needs Guidance \(Version 3.0\)](#), Appendix 4, for more registry guidance.

### Challenges

Jurisdictions face several challenges in operating and maintaining registries. Common issues encountered by jurisdictions include low levels of participation in the registry and difficulty educating the public about what the registry is and the services it provides to registrants. Further, jurisdictions must ensure that information within the registry is as up-to-date as possible, a process that can be time consuming.

### Registry Participation

Jurisdictions may encounter difficulties encouraging eligible individuals to participate in a registry. Some individuals with disabilities or other functional needs may lack trust in the government and be unwilling to provide personal or medical background information to a government agency. Others believe their sensitive information may not be protected by the registry, making them vulnerable to identity theft and fraud. Some individuals, such as undocumented workers, may fear the legal consequences of providing their information to the government.

Individuals may also be reluctant to participate in a special needs registry due to a lack of familiarity with what a registry is and what services are provided through it. Individuals with disabilities or other functional needs may believe that they do not need assistance during an emergency. Finally, some individuals have disabilities or other functional needs that are temporary and do not believe it is worth participating in a registry for the duration of their situation.

### Communicating the Purpose of the Registry

Jurisdictions must identify ways of publicizing the registry to encourage the participation of eligible individuals. Jurisdictions must communicate what registration means and what services are available to registrants. Further, jurisdictions should inform individuals of the processes in place to keep information secure to assure them that their personal information will be protected.

For more information about promoting special needs registries, see the *Lessons Learned Information Sharing (LLIS.gov)* Lesson Learned, [Disaster Assistance Registries: Conducting Outreach Through Trusted Organizations](#), and the *LLIS.gov* Practice Note, [Disabilities and Other Special Needs: Monroe County, Florida's Strategy to Promote its Special Needs Registry](#).

Many jurisdictions experience difficulties engaging eligible individuals. Personnel who manage registries often believe their messages reach only a small fraction of the population that would benefit from participating in the registry. Jurisdictions employ various methods to engage the community including encouraging community partners to share information about the registry with their members, publicizing the registry through the media, and exhibiting or presenting at conferences and meetings.



## **Maintaining Registry Information**

Jurisdictions face the constant challenge of maintaining information in the registry. Out-of-date or incorrect information can hinder rather than facilitate emergency response and planning efforts. Jurisdictions can keep registries up-to-date by requiring that registrants update their information annually, at a minimum. However, notifying registrants to update their information and the process of manually updating registrants' profiles in an electronic database can be time-consuming and costly. Thus, jurisdictions must determine which method will be most effective in soliciting information updates from registrants.

## **Staffing**

Jurisdictions use various means to staff their special needs registries. For example, some jurisdictions have dedicated special needs coordinators that manage registries as one of their job responsibilities. Other special needs registries are managed by emergency management or other county or local personnel that provide support to the registry. However, operating and maintaining a registry is a labor-intensive process. Activities such as entering new registrant information into the registry, updating registrants' information, contacting registrants during disasters, and promoting the registry require significant manpower. As a result, volunteers are frequently an essential resource for operating and maintaining registries, particularly during emergencies or evacuations. These volunteers can come from organizations such as the Medical Reserve Corps.

## **Ensuring Registry Matches Needs of Community**

Jurisdictions should work closely with individuals with disabilities and other functional and access needs and the organizations and agencies that they associate with to ensure that registries serve the needs of the community. By engaging individuals and community organizations, jurisdictions can determine what type of registry to develop. For example, some communities may require a medical special needs registry, while other communities may benefit from a registry that is used only for communications and warnings. This coordination will enable the departments and agencies that operate special needs registries to leverage funding and staffing resources effectively and to employ those resources appropriately to provide the required registry services.

The [National Response Framework](#) provides a definition of special needs. Jurisdictions can use this definition to determine the type and purpose of their registry.

## **RESOURCES**

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Utah Special Needs Registry.

<http://www.specialneedsutah.org/>

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